

Developmental Disabilities Council
Meeting Minutes
Wednesday, May 10, 2017
Margaret M. O'Neill Building, Dover, DE
DHSS Admin Building, Herman Holloway Campus, New Castle, DE
6:00 p.m.

Members Present: Barbara Monaghan (Chairperson), Carol Barnett, Alex Eldreth, Alvin Emory Jr., Karen Gallagher, Lillian Gibbons, Laura Greene, Terri Hancharick, Michael Harris, Brian Hartman, Esq., Nancy Lemus, Katie Macklin, Karen McGloughlin, Carrie Melchisky, Joseph Merritt Jr., Beth Mineo, Angela Mitchell, Sue Ellen Powell, Steven Yeatman

Members Absent: Maitri Campbell, Angela Ehst, Katie Howe, Rick Kosmalski, HarrietAnn Litwin, Debra McCann, Daniese McMullin-Powell, Shawn Rohe, Jill Scannell

Staff Present: Pat Maichle, Kristin Harvey, Stefanie Lancaster, Emmanuel Jenkins

Guests: William Monaghan Jr., Victoria Counihan, Cheryl Bates-Harris, Ed Gootzait

- I. Call to Order** – Barbara Monaghan called the meeting to order at 6:06pm.
- II. Approval of Minutes** – Terri Hancharick made a motion to approve the minutes as submitted. Steve Yeatman seconded the motion. The minutes were approved by Council.
- III. Approval of Agenda** – Joseph Merritt Jr. made a motion to approve the agenda as submitted. Terri Hancharick seconded the motion. The agenda was approved by Council.
- IV. 5 Minute Public Comment Period** – Angela Mitchell stated she was just appointed to the Christina School District School Board. The Council congratulated her.
- V. Chair's Report** – Barbara stated that the Dover YMCA recently unveiled their newly-installed harness system at a press conference. The harness system allows individuals with physical disabilities to use the YMCA's exercise equipment and take part in group fitness classes. Barbara spoke at the press conference about how having the harness system available for her to use when at the YMCA has helped her life and allowed her to exercise again.
- VI. Staff Report** – Pat stated the following:
 - * Delaware Developmental Disabilities Services (DDDS) and the DDC are hosting a Community of Practice for Supporting Families Across the Life Course training on June 12th, 2017 from 10am – 3pm at the DDDS Fox Run Office. A flyer was shared with all members.

- * DDDS has a new provider for Targeted Case Management, The Columbus Organization which is a national Commission on Accreditation of Rehabilitation Facilities (CARF-accredited organization). This agency will provide services to those that live with their families or those that live in group homes. This is an important change to the way DDDS currently does business.
- * There are currently significant budget reductions recommended by the Governor to the DDDS budget. The recommended reduction in funding at this time is \$60,800,000 for 2018 (11% of their total budget).
- * Elder Abuse Recognition Day is June 15th. On this day, many of the offices surrounding Legislative Mall put up purple lights in the windows to recognize this day.
- * After five years of advocacy, the Tobacco Risk Surveys are now including students with disabilities. The University of Delaware (U of D) and Division of Substance Abuse and Mental Health (DSAMH) are working to help make accommodations to those that need help completing this survey while maintaining the validity of the survey and anonymity of the students.
- * Representative Longhurst approached Pat 5 months ago about how the state might be able to better respond and interact with individuals with disabilities who are drivers. DelDOT is exploring the possibility of adding a universally recognized symbol to driver's licenses. The hope is that the symbol will be recognized and help with interactions with police and other emergency personnel.
- * Pat has been working with other Councils to find a way for home health agency nurses to cross over two county lines. Pat has been working with Mary Peterson with the Division of Long Term Resident Protection to address regulations to help alleviate this problem. If an individual lives in New Castle County, the individual can not be transported to Sussex County and ask their nurse to attend. Alvin Emory stated he addressed this concern when his wife had to be transported. Director Peterson of DLTCRP is researching this problem to find a reasonable solution.
- * Pat was involved in a telehealth group a few years ago. The report that was developed from this workgroup was recently published and distributed. Pat has a hard copy of the report if anyone would like to read it and she has sent it to members via email.

VII. Financial Report

Financial Advisory Committee Report – The 2017 grant year is going smoothly. The Omnibus Bill from the Federal Government states that the Delaware DDC will receive the same amount of grant funding this year as we did last year. The 2016 funds that show remaining need to be obligated by September 30th of this year and spent by September 30th next year. The RFPs being voted on this evening, if approved by Council, will obligate the remaining 2016 funds.

VIII. Current Business

1. **Legislative Update** – Pat stated that the Council is currently tracking approximately 30 Bills. Some of those Bills are as follows:

- a. HB21 Organ Transplant Bill. Representative Heffernan is working to get this Bill heard on the Senate floor.
 - b. SB 38 Real Estate Tax exemption Bill
 - c. Behavioral Health Transition Bill
 - d. 4 Marijuana Bills – Three of which are related to the use of Medical Marijuana
 - e. HB142 Seclusion and Restraint Bill that the Governor’s Advisory Council for Exceptional Citizens (GACEC) is supporting.
 - f. HB160 End of Life Bill
 - g. Homeless Bill of Rights Bill
 - h. Victim Bill of Rights Bill
 - i. HB12 Funding for K-3 Special Education
 - j. HB 145 regarding ABLE Accounts
 - k. HB120 relating to insurance coverage of certain cancer treatments
 - l. HB79 relating to Voter registration
 - m. HB140 relating to infants with prenatal substance exposure
2. **Self-Advocacy Organization Update** – Bill stated that Delaware People First will be having a Self-Advocacy Conference at Dover Downs on Saturday, May 20th. This year’s conference is titled “Self-Advocacy - Into the Future”. If any member would like to attend and has not registered please do so. There will be guest speakers from Washington, DC and Michigan. A copy of the flyer has been posted on the DDC website.
 3. **Strategic Planning – Prepare for July Approval** – Pat stated the Council has the opportunity to make any edits needed to the Strategic Plan. All changes must be submitted to our Federal Granting Agency in August. All Committees have been asked to review the document. Any recommended changes will be voted on at the July Council meeting. As it is the first year of the plan, the Council may wish to make no changes at this time.
 4. **NACDD Conference/Annual Technical Assistance (TA) Institute – July DDC Meeting Date Change** – The DD Council meeting in July was scheduled for the second Wednesday of the month. Unfortunately, that is the same week as the NACDD Conference. Kristin and Pat have been asked to make presentations at this conference. Kristin will be speaking about Delaware’s Junior Partners in Policymaking Program. Pat will be speaking along with Katie Macklin and Sara Weir of the National Down Syndrome Society regarding the correlation between individuals with Down syndrome and early onset of Alzheimer’s disease. Barbara agreed to move the meeting to July 19th at 9:30am. Due to being unable to locate a New Castle County site that has videoconferencing capabilities available on this date, it was decided to have the meeting in one location at the Outlook at the Duncan Center here in Dover. Pat will notify the July guest speaker of the change in date and location.

IX. Committee Reports

Membership – Karen Gallagher reported that the Membership committee will be having a meeting in the next few months. Pat will schedule this meeting so that the ballot for September's Council meeting can be developed. The Council is still working with the Governor's office to check on the status of Derrick George's application to be a member of the Council.

Children & Families –

1. Draft RFP – Access to Free or Low Cost Health/Exercise Programs –

Alex Eldreth stated a copy of RFP 1705 was handed out to all those present. One of the Children and Families Committee goals within the Five Year State Plan is to increase the knowledge base of the disability community, as well as that of policymakers, on resources available to access free or low cost health and wellness programs. The committee decided that someone professional needs to do the research to find out what is available. There are options available but you need to know where to look. This RFP will provide funding up to \$25,000 to help collect data and input to create, market, and distribute materials for a public awareness campaign focusing on the benefits of providing free or low-cost access to health and wellness activities for people with developmental disabilities. Alex stated that the Children and Families Committee requests the Council to review and ask any questions. Barring any real issues, the committee asked Council to vote to approve this RFP. Brian recommended sending the RFP back to the Committee to provide more guidance on definition of health and wellness. Nancy stated that nutrition should be added as there is a lot involved with nutrition for individuals with feeding tubes. Alex made a motion that after the Committee makes necessary changes to the RFP the Executive Committee can vote on and approve the revisions at their June meeting. After a vote, the Council decided that this was the best option for this RFP.

Policy & Law – Terri Hancharick asked if the Council received any proposals for the Self-Advocacy RFP. Pat stated no proposals were received. The Council has the option to directly or indirectly assist a self-advocacy organization through this project. Pat stated the Council can fund an individual to help mentor a self-advocacy organization as the Council did this fiscal year with Jamie Wolfe. Pat stated that since no proposals were received, Jamie could do it again this fiscal year. Nancy Lemus questioned if the Delaware Statewide Programs submitted a proposal for the self-advocacy RFP. Kristin stated that the proposal she is referring to was received May 9th but was not for the self-advocacy RFP. It was received as an unsolicited proposal that will be assigned to a Committee and discussed at a future date.

Adult Issues –

1. Proposal of Sex Education Program – Review and Approval – Terri

Hancharick reported that the Council received two proposals in response to the

RFP1701. The Adult Issues Committee chose the proposal from Nemours Alfred I. duPont Hospital for Children. This proposal is to develop and facilitate a new series of workshops aimed at healthy sexuality education for young adults with disabilities and a separate program for their parents/caregivers. While many teens are exposed to basic sexuality education through middle or high school health curricula, young adults with disabilities often do not have access to the same curriculum, either because it was not thought to be important for them or because they were pulled out for therapies during the times that their peers were receiving Sex Ed instruction. This inappropriately leaves young adults with disabilities lacking potentially life-changing information about puberty, sexual development, healthy sexual relationships and consent. Terri stated that the Adult Issues Committee's request for approval of the Nemours proposal comes as a motion from the Committee. Karen McGloughlin stated she had reviewed the proposal and there are already existing programs in Delaware similar to this. The Committee stated this would not be repetitive work. The motion comes from Committee with approval for this RFP in amount of \$20,000. The motion to approve the proposal was approved by majority vote, with one Council Member opposing.

2. **RFP 1704 Down Syndrome/Alzheimer's Public Awareness Campaign – Review and Approval** – Terri Hancharick stated RFP1704 is for funding up to \$25,000 to help create, market and distribute material for a factual public awareness campaign focusing on the correlation between individuals who have Down syndrome and the development of early onset Alzheimer's disease. The target audience for the receipt of the educational materials is: individuals with Down syndrome, families/caregivers and also Delaware key policymakers. The motion to approve comes from the Adult Issues Committee to approve this RFP in the amount of \$25,000. After some lengthy discussion, it was decided by Council that this RFP did not need any more detail. After no further discussion, no opposed, no abstentions, this RFP was approved by Council.

Partners Oversight -

1. **Jr. Partners in Policymaking Program 2017** – Pat stated a schedule for the Junior Partners in Policymaking Program was provided in the packets of information given at this meeting. Pat stated that Council Members should please feel free to attend. This year, the program will be held at Delaware State University, and will run from June 18 through Friday, June 23rd. At suggestion from Victoria Counihan, Deputy Attorney General (DAG) for the Council, Emmanuel has created a separate page on the DD Council's website to distinguish between the Adult Partners in Policymaking Program versus the Junior Partners in Policymaking Program. Members should look at the new pages at this link, <http://ddc.delaware.gov/policymaking.shtml> and <http://ddc.delaware.gov/policymaking-jr.shtml>.

2. Consumer Caucus – Saturday, May 13th, is the next Consumer Caucus committee meeting that will be held at the ChesDel Restaurant. Please let DDC staff know if you want to attend so they can plan accordingly.

X. New Business

1. Presentation by Cheryl Bates – Harris (NDRN) – Employment –

Barbara Monaghan introduced Cheryl Bates-Harris, from the National Disability Rights Network (NDRN). Cheryl recently was a guest speaker at the Center for Disabilities Studies (CDS) Lunch and Learn where she showed a film titled, “Bottom Dollar”. This is a documentary from the NDRN in Washington, DC regarding sub-minimum wage. The documentary begins by discussing how sub-minimum wage is legal due to the Fair Standard Labor Act. This was used even after de-institutionalization began. Continued use of the provisions in the Fair Standard Labor Act has progressed to a point where businesses are making a lot of money paying people for work that is not based on productivity. The documentary presents information about sub-minimum wage and leads the viewer through the stories of people with disabilities showing how they used various methods and their own self-determination to transition from working in a sheltered workshop earning sub-minimum wage to competitive employment and receiving real wages just like their peers without disabilities.

Cheryl stated that many people are in denial about their child’s significant disabilities and their abilities to sustain a career. Andy –the actor in the video– had a diving accident and was in a coma for seven months. The doctors told Andy’s mom that he was going to be a “vegetable” (their words) for the rest of his life. Andy currently holds a position at a local store where he scans store inventory. Andy works along side of an individual without a disability. Part of the reason Andy is so successful is because when he was in high school, the school offered transition workshops to help him and he started working five days after graduation. Prior to entering competitive employment, Cheryl stated that Andy spent 15 years in a sheltered workshop.

The video discusses the sub-minimum wage issue. Cheryl stated that these individuals are not given options. Many do not know about vocational rehabilitation services. Cheryl stated that the NDRN believes in self-directed services. Karen Gallagher asked Cheryl in a Q&A session at the end of her presentation if possible budget cuts will affect the ability of people with disabilities to work for a competitive wage. Cheryl said it may. The Rehabilitation Act 1973 says serve those with most significant disabilities first. Medicaid dollars pay for services and use outcome money to support outcomes.

Pat will get a copy of the DVD from Cheryl and anyone that would like a copy can go do www.bottomdollar.com and order one.

2. Future Speakers – The guest speaker for July will be Lanny Edelson who will be discussing intentional communities. Brian Freedman will be speaking

at the September Council meeting to discuss the work that the University of Delaware is doing on Autism. Jane Donovan will come in November to discuss the risk surveys currently being done in schools.

- 3. Annual DDC Meeting – September** – The Annual Election of Officers will be held at the September Council meeting which will be held at the Outlook at the Duncan Center in Dover on September 13th from 6:00 pm to 8:30 pm.
- XI. Other Council Business** – There was no other business to report at this time.
- XII. Adjournment-** The meeting was adjourned at 7:53pm.